

# SO I HAVE A CYSTIC FIBROSIS GENE, BUT MY PARTNER'S TEST WAS NEGATIVE



Published by PacNoRGG  
The Pacific Northwest  
Regional Genetics Group

**You have had a cystic fibrosis (CF) carrier test that showed you are a carrier. But your partner's test was "negative." Now what?**

## How do you know I am a carrier for CF?

The blood test looked for the most common changes in the pair of CF genes. Since you have one of these common changes in one of these genes, you are a carrier.

## What is a carrier?

A carrier is someone who has one changed gene (mutation) for the disease CF. Genes do not change during one's lifetime, so a carrier will always be a carrier, but will never get sick with CF. Carriers do not need any special medical care. People with CF always have two changed genes.

## What is CF?

CF is a disease that causes breathing and digestion problems. Symptoms usually begin in the first year of life and get worse over time. Some children are very sick; others are not. Problems may include coughing, repeated pneumonia, lung damage, diarrhea and poor growth. People with CF are not mentally retarded. Their appearance is not affected. Life is usually shortened, but most children with CF live 20 to 35 years. There is no cure. Treatment is usually medicine and physical therapy.

## My partner's test is negative. Can he still be a carrier?

Yes. Although the chance your partner is still a carrier is small, it is never zero. More than 900 different changes can happen in the CF gene. The test only looks for about 25 of these. Some people have a change the test does not look for. Since no change was found, there is only a small chance your partner is still a carrier. The exact chance depends on your partner's race. Your health care provider or a genetic counselor can figure out this chance for you.

## What is the chance I will have a baby with CF?

Your chance to have an affected baby is small. Two things have to happen for you to have a baby with CF. First, both you and your partner must be carriers. Then, the baby must inherit the changed CF gene from both you and your partner. When both parents are carriers, the chance the baby will be affected is 1 in 4 (25%). Your chance of having a baby with CF will certainly be smaller than 1 in 4, and is probably less than 1%. Your health care provider or a genetic counselor can figure out this chance for you.

## Can we test the baby?

### *During pregnancy:*

Yes, but the results will not be very accurate. If your partner has a changed gene that the test does not look for, the changed gene will not be found in the baby either. You should talk to a genetic counselor to understand more about what the test on the baby could tell you, as well as the chance the test could cause a problem in your pregnancy.

### *At birth:*

Yes, but again, the results will not be very accurate.

### *A few months after birth:*

Yes. The baby can have a different test for CF that will be more accurate. This test is usually done when a baby has some symptoms of CF. You should talk to your health care provider about if and when your baby should have this test.

## Should I tell other people in my family?

Since you are a carrier for CF, other people in your family may be too. You could suggest they talk to their health care provider or a genetic counselor to see if they want to be tested.

## How can I get more information? How can I decide what to do?

Talk to your health care provider or see a genetics specialist, a genetic counselor. A genetic counselor is specially trained to help you decide what is best for you. A genetic counselor will answer your questions about the blood test results, the testing you could have in the pregnancy and answer any other questions you have about CF.

This fact sheet was written by the PacNoRGG (Pacific Northwest Regional Genetics Group) Education and Prenatal Genetics committees and is consistent with the 2001 Clinical and Laboratory Guidelines, *Preconception and Prenatal Carrier Screening for Cystic Fibrosis*, published by the American College of Obstetricians and Gynecologists and the American College of Medical Genetics. More detailed patient brochures, *Cystic Fibrosis Carrier Testing: The Decision is Yours*, and *Cystic Fibrosis Testing: What Happens If Both My Partner and I Are Carriers?* can be purchased from ACOG, [www.acog.org](http://www.acog.org); (202)863-2518.

PacNoRGG is funded in part by project #MCJ-411002-13 of the Maternal and Child Health Bureau, Department of Health and Human Services.

This brochure is available on the PacNoRGG web site:  
<http://mchneighborhood.ichp.edu/pacnorgg>

April 2002





**Dear Colleague,**

The Washington State Department of Health (DOH) is pleased to provide camera-ready art for printing this educational material. To ensure that the original quality of the piece is maintained, please read and follow the instructions below and the specifications included for professional printing.

- **Use the latest version.** DOH materials are developed using the most current information available, are checked for clinical accuracy, and are field tested with the intended audience to ensure they are clear and readable. DOH programs make periodic revisions to educational materials, so please check this web site to be sure you have the latest version. DOH assumes no responsibility for the use of this material or for any errors or omissions.
- **Do not alter.** We are providing this artwork with the understanding that it will be printed without alterations and copies will be free to the public. Do not edit the text or use illustrations or photographs for other purposes without first contacting us. Please do not alter or remove the DOH logo, publication number or revision date. If you want to use a part of this publication for other purposes, contact the Office of Health Promotion first.
- **For quality reproduction:** Low resolution PDF files are intended for black and white or color desktop printers. They work best if you are making only one or two copies. High resolution PDF files are intended for reproducing large quantities and are set up for use by professional offset print shops. The high resolution files also include detailed printing specifications. Please match them as closely as possible and insist on the best possible quality for all reproductions.

If you have questions, contact:  
Office of Health Promotion  
P.O. Box 47833 Olympia, WA 98504-7833  
(360) 236-3736

**Sincerely,**  
**Health Education Resource Exchange Web Team**